



Advanced melanoma of the skin Tonapuku maukaha o te kiri



Endorsed by:



**NEW ZEALAND ASSOCIATION
of Plastic Surgeons**

Understanding Cancer

A guide for people with advanced melanoma of the skin

ANY CANCER, ANY QUESTION 0800 CANCER (226 237) Cancer Information Helpline

Your general practitioner: phone _____

Your cancer team: phone _____

Your local Cancer Society: phone _____

24-hour emergency: phone 111

Copyright © 2018 Cancer Society of New Zealand Inc,
Te Kāhui Matepukupuku o Aotearoa

PO Box 651, Wellington 6140

Third Edition 2018

ISBN 978-0-9951112-0-2

You can get copies of Cancer Society booklets and information sheets from your local Cancer Society by phoning the Cancer Information Helpline **0800 CANCER (226 237)** or by downloading them from our website www.cancernz.org.nz.

More information about the Cancer Society can be found at the back of this booklet.

We would value your feedback on this booklet. There is an online form you can fill in on our website:

www.cancernz.org.nz/cancer-information/other-links/feedback/

About this booklet

Melanoma is a cancer of the skin. It is the most serious of the three common forms of skin cancer, the other two are basal cell carcinoma and squamous cell carcinoma. Occasionally, melanoma starts in other parts of the body also.

Advanced melanoma of the skin is cancer that has spread beyond the original primary cancer in the skin.

In this booklet you will learn about advanced melanoma of the skin. It will help you understand an advanced melanoma diagnosis, the type of treatment you might have, and about living with advanced melanoma.

Ngā kōrero mō te pukapuka nei

He matepukupuku ō te kiri te tonapuku, a, koinei te matepukupuku taumaha rawa atu ō ngā momo matepukupuku ō te kiri e toru (ko te basal cell carcinoma me te squamous carcinoma ērā atu). Ko te matepukupuku kua rauroha ki tua atu ō te matepukupuku matua i roto i te kiri.

I tēnei pukapuka iti, ka ako koe i ngā āhuatanga e pā ana ki tonapuku maukaha.

Words in bold are explained in the glossary (what does this word mean).

“When I was diagnosed I was very frightened and vulnerable to misinformation and suggestion by well-meaning people. I wanted, and mostly got, information and positive encouragement, which gave me hope.”
Phil

“The Cancer Society is a committed advocate on behalf of people with cancer. We were part of the campaign that supported funding for new, advanced melanoma therapies, and pembrolizumab (Keytruda) and nivolumab (Opdivo) are now fully funded by PHARMAC. These breakthrough medicines are new immunotherapies that can help boost the body’s natural defences against cancer.

“As a non-profit organisation with no direct financial support from the government, the Cancer Society can independently inform and lobby, influencing positive change like this. We work hard to highlight issues publicly in the media, and to also work with government officials, ministers, the government, opposition parties and other organisations.”

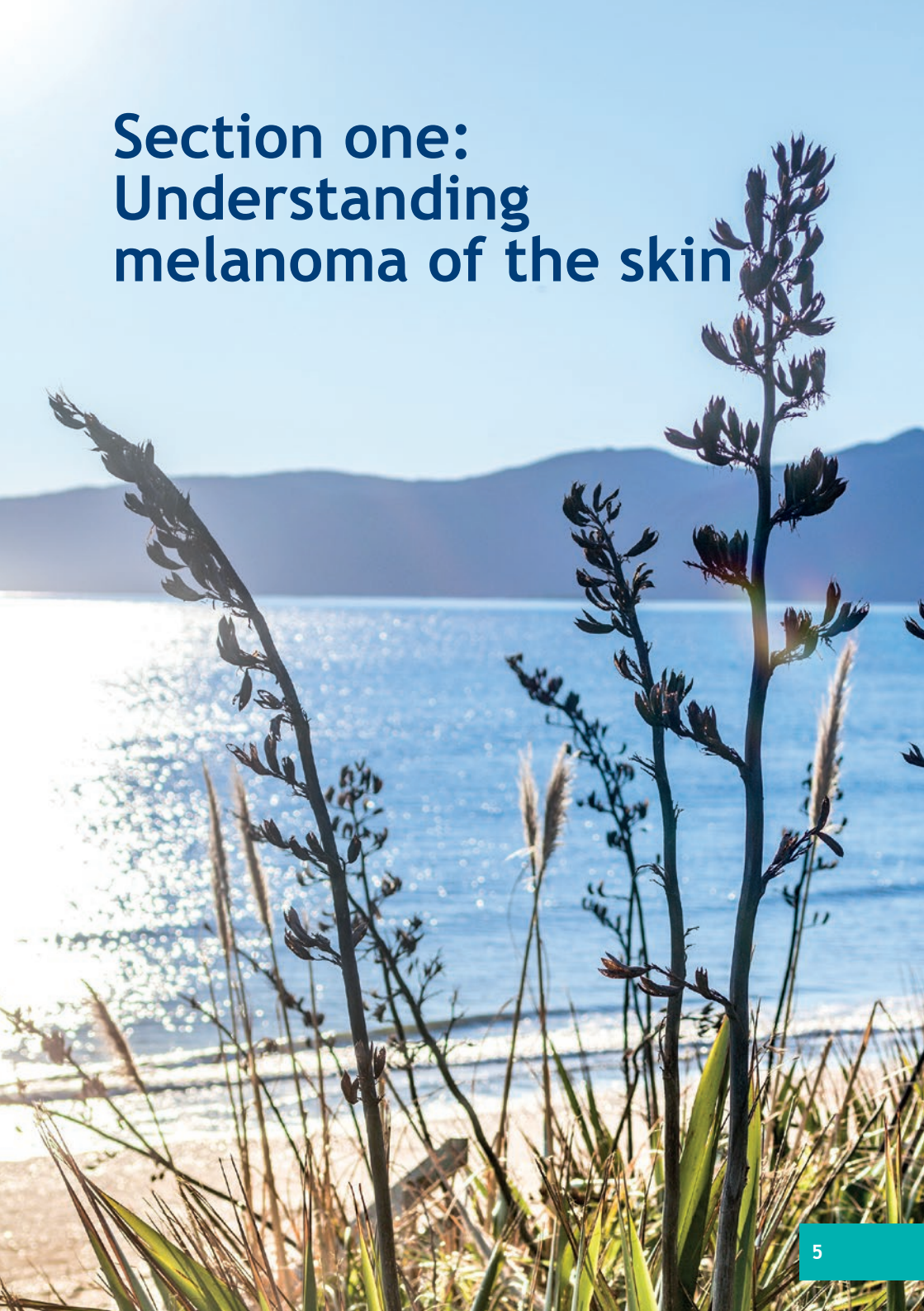
Chris Jackson, Cancer Society Medical Director

Contents

| | |
|-------------------------------------------------------------------------------------|----|
| <u>Section one: Understanding advanced melanoma of the skin</u> | 5 |
| Key points | 6 |
| How skin cancer develops | 7 |
| What is melanoma | 7 |
| What is advanced melanoma? | 9 |
| <u>Section two: How advanced melanoma is diagnosed</u> | 10 |
| Key points | 11 |
| How advanced melanoma is diagnosed | 11 |
| The stages of melanoma | 13 |
| Your pathology report | 14 |
| Questions you may want to ask your melanoma treatment team about diagnosis | 16 |
| <u>Section three: Treatment for advanced melanoma of the skin</u> | 17 |
| Key points | 18 |
| Treatment for advanced melanoma of the skin | 20 |
| Your treatment team | 20 |
| Talking to your treatment team | 21 |
| You can ask for a second opinion | 21 |
| How surgery is used in treatment for advanced melanoma | 22 |
| Surgery to remove lymph nodes | 23 |
| How radiation treatment is used for advanced melanoma of the skin | 23 |
| Side effects of radiation treatment | 24 |
| Targeted treatments for advanced melanoma | 24 |
| Immunotherapy treatment for advanced melanoma of the skin | 25 |
| Side effects of targeted treatments and immunotherapy | 25 |
| More information about targeted treatments for advanced melanoma | 26 |
| More information about immunotherapies for advanced melanoma | 27 |
| The availability of new therapies for advanced melanoma | 27 |
| Taking part in a clinical trial | 28 |
| How chemotherapy is used for advanced melanoma | 29 |
| Side effects of chemotherapy | 29 |
| Traditional Māori healing | 30 |
| Pacific traditional healing | 31 |
| Palliative care | 31 |
| Complementary and alternative therapies | 33 |
| How to look after yourself following treatment | 33 |
| Regular check-ups | 33 |
| Protecting your skin | 35 |
| Applying sunscreen | 36 |
| Some questions you may want to ask your treatment team after treatment | 36 |
| <u>Section four: Living with advanced melanoma of the skin</u> | 37 |
| Key points | 38 |
| Coping with advanced melanoma symptoms and side effects | 39 |
| Coping with Fatigue | 39 |

| | |
|--------------------------------------------------------------------------|----|
| Changes to your eating habits | 40 |
| Dealing with pain | 40 |
| Changes in appearance after surgery..... | 41 |
| Sex and advanced melanoma | 41 |
| Fertility and contraception when you have advanced melanoma..... | 42 |
| Risks of developing lymphoedema after surgery and radiation treatment .. | 42 |
| What is lymphoedema? | 42 |
| The lymphatic system | 43 |
| Coping with feelings and relationships | 44 |
| Psychological, social and counselling support available to you | 44 |
| How families/whānau can help | 45 |
| You may have changes in your employment | 46 |
| If you continue to work..... | 47 |
| If you can no longer work | 47 |
| Using your work entitlements: sick leave and annual leave | 48 |
| Returning to work | 48 |
| Financial and legal support..... | 49 |
| Financial support—benefits and entitlements..... | 49 |
| Talking to your bank..... | 49 |
| Personal insurance benefits..... | 49 |
| What is power of attorney? | 50 |
| How to make a will | 51 |
| Advance care planning | 51 |
| Looking after yourself when you have advanced melanoma | 52 |
| Relaxation techniques | 52 |
| Cultural and spiritual support | 53 |
| Interpreting services | 53 |
| Questions you may like to ask after treatment | 53 |
| Appendix A: Suggested websites | 54 |
| Appendix B: Understanding cancer | 55 |
| What is cancer? | 55 |
| How cancer starts | 55 |
| How cancer spreads | 56 |
| Appendix C: Understanding the skin | 57 |
| Understanding the skin..... | 57 |
| The epidermis layer of the skin | 57 |
| The dermis layer of the skin | 57 |
| Appendix D: Understanding melanoma | 58 |
| Who gets melanoma?..... | 58 |
| Risk factors for melanoma | 58 |
| Causes of melanoma | 59 |
| Notes..... | 60 |
| Glossary (what does that word mean?) | 61 |
| Cancer Society Information and Support Service contact details | 64 |
| Acknowledgements | 67 |

Section one: Understanding melanoma of the skin



Key points

- Melanoma is a cancer of the skin and is the most serious of the three common forms of skin cancer.
- Advanced melanoma means that your melanoma has spread from where it first started to another part (or parts) of your body.
- The different stages of melanoma take into account how thick the original melanoma was.
- It also considers if it was ulcerated or not, and whether it has spread to other parts of the body. Advanced melanoma relates to stages three and four.

Ngā kōrero matua

- He momo matepukupuku ō te kiri te tonapuku, koinei te mea taumaha rawa atu ō ngā momo matepukupuku e toru ō te kiri. Ko te tonapuku maukaha, ko te matepukupuku kua rauroha ki tua atu ō te wāhi tuatahi i kitea.
- Ka puta te tonapuku maukaha ka rauroha ana te tonapuku ki tua atu ō te wāhi i puta tuatahi ki te kiri.
- Ka hāngai ngā wāhanga ō te tonapuku ki te mātatoru ō te tonapuku tuatahi i puta. Ka hāngai anō hoki mehemea i te ipuipu te matepukupuku kīhai rānei, mehemea kua rauroha ki wāhi kē ō te tinana. Ka puta te tonapuku maukaha i ngā wāhanga toru me te whā.

How skin cancer develops

Like all body **tissue**, the skin is made of tiny ‘building blocks’ called cells. These cells can sometimes become cancerous when they have been damaged, for example by **ultraviolet (UV) radiation from the sun**. Skin cancers are named after the types of cell they begin to grow from. The three most common types of skin cancer are basal cell carcinoma, squamous cell carcinoma and **melanoma**.

What is melanoma

Melanoma is a cancer of the skin and is the most serious of the three common forms of skin cancer. Advanced melanoma is cancer that has spread beyond the original primary cancer in the skin. When your melanoma has spread from where it has first started to another part (or parts) of your body it is called advanced melanoma.

The different stages of melanoma are related to how thick the original melanoma was. They also relate to whether it was ulcerated or not, and whether it has spread to other parts of the body. Stage three and four melanoma is called advanced melanoma.

A melanoma is a cancer that develops from melanocytes (pigment cells). Melanoma most commonly occurs in the skin on parts of the body that were sunburned, but it can appear in skin anywhere on the body.

Go to Appendix C to understand more about the skin.

Melanoma can start in parts of the body other than the skin, but this is very uncommon. Other parts of the body where melanoma can start include:

- the eye (ocular melanoma)
- the mouth, gastrointestinal tract (gut), vulva, vagina or anus (mucosal melanoma)
- under fingernails or toenails (subungual melanoma).



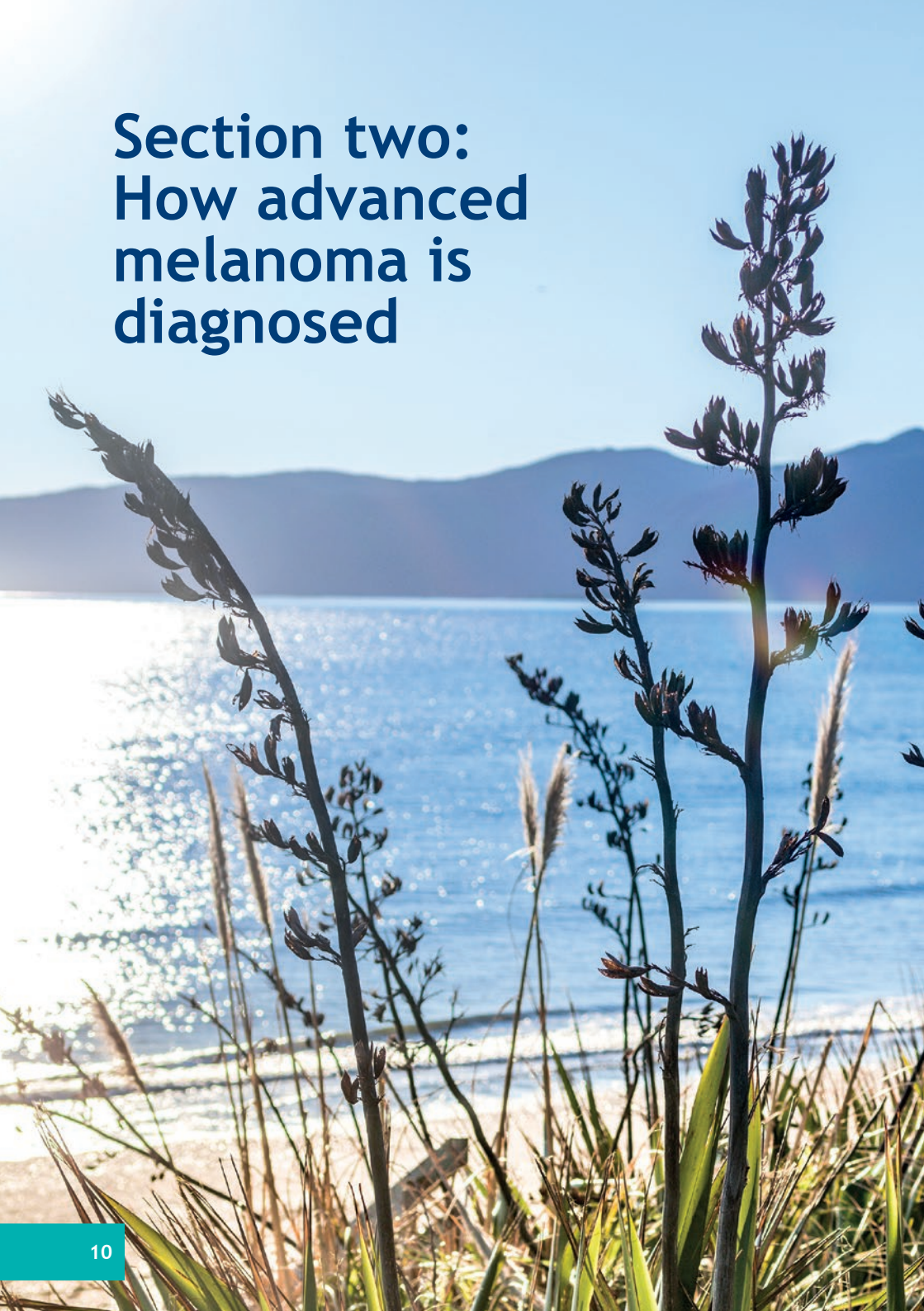
What is advanced melanoma?

Advanced melanoma is diagnosed when your melanoma has spread from where it first started to another part (or parts) of your body. Melanoma can spread to almost any part of your body, but it is most likely to spread to one or more of the following places:

- skin (away from your original melanoma)
- lymph nodes
- lungs
- liver
- bones
- brain

“ *I was very scared when I learned I had melanoma. But I knew I was in good hands. The New Zealand specialists know about melanoma, how to test for it, what to look for— they were very thorough, understanding and kind.* **”**
Karen

Section two: How advanced melanoma is diagnosed



Key points

- The first sign of melanoma is usually the appearance of a new spot or a change in an existing freckle or mole.
- If your GP suspects you have advanced melanoma you will be referred to a hospital doctor who may recommend some further tests.
- This waiting period can be an anxious time and it may help to talk things over with someone.

Ngā Korero Matua

- Ko te tohu tuatahi mō te tonapuku, ko te puta o tētahi kōiraira hou, tētahi panonitanga rānei ki tētahi iraira, tētahi tiwhanga rānei.
- Mehemea ka whakaaro tō rata kua pāngia koe ki te tonapuku maukaha, ka tonoa koe ki te haere ki tētahi rata hōhipera, tērā pea ka taunaki ia kia whai anō koe i ētahi whakamātautau anō.
- He wā uaua te wā tatari i ngā korero, nō reira tērā pea, he pai ki te kōrerorero mō ngā piki me ngā heke me tētahi atu.

How advanced melanoma is diagnosed

The first sign of melanoma is usually the appearance of a new spot or a change in an existing freckle or mole. The change may be in size, shape and/or colour and is normally noticed over several weeks or months rather than days.

If you have a spot or mole that you are worried about, or are concerned that your melanoma has returned, the first person you will see is your family/whānau doctor (GP). They will look at any skin changes that you are concerned about, using a **dermoscope/dermatoscope**. They may also feel the **lymph nodes** in the area nearest your spot or mole.



A doctor using a dermatoscope to take a photo of skin changes.

If your doctor suspects that you have advanced melanoma, even if you have never been diagnosed with melanoma before, you will be referred to a hospital doctor who may recommend further tests. Depending on your symptoms, these further tests may include:

- **biopsy**
- **fine needle aspiration**
- **sentinel node biopsy**
- blood tests
- other tests such as a **CT scan or PET scan**

After any test it is a good idea to ask where and when you will get your results. This can vary according to the hospital or doctor you see, so it is important that you have clear expectations and an understanding of the likely timeframes.

If you have not been given this information, call your GP or the treatment team to make sure an appointment has been arranged.

This waiting period can be an anxious time, so it may help to talk things over with a family/whānau member or close friend.

The stages of melanoma

Knowing the stage of your melanoma helps your treatment team to plan your treatment. ‘**Staging**’ is based on the results of your surgery and any other tests you may have had. It describes the thickness of your melanoma, if there is any ulceration, and whether it has spread to other parts of your body.

Advanced melanoma occurs in stages three and four.

This table is a simplified version of how melanoma is staged.

| | |
|-------------------------------|--------------------------------------------------------------------------------------------------|
| Stage 0 (melanoma in situ) | Abnormal cells are found in the epidermis |
| Stage 1 | Melanomas are no more than 2mm thick and may or may not be ulcerated |
| Stage 2 | Melanomas that are more than 2mm in depth but haven’t spread to any lymph nodes or distant sites |
| Stage 3 | Any thickness that has spread to lymph vessels or lymph nodes |
| Stage 4 | The melanoma has spread to other parts of the body |

Your pathology report

If you have melanoma, the **pathologist** will prepare a report that provides your treatment team with information to help determine the stage of your melanoma and plan your treatment. The following factors may be included:

Breslow thickness

This is a measure of the thickness of the melanoma in millimetres. Melanomas are classified into four categories:

- less than 1mm (most melanomas are this category)
- 1-2 mm
- 2.1-4 mm
- greater than 4 mm

Margins

Margins identify if any cancer cells are seen near the outer edge of the tissue sample that has been removed. If cancer cells come close to the edge you may need further surgery.

Mitotic rate - describes how quickly melanoma cells are dividing. The higher the mitotic rate, the faster the melanoma may be growing.

Clark level

This describes how deeply the cancer has gone into layers of the skin. It is not widely used anymore.

Ulceration

The breakdown or loss of the epidermis (top layer of the skin). Ulceration is determined by the pathologist when the specimen is examined under a microscope.

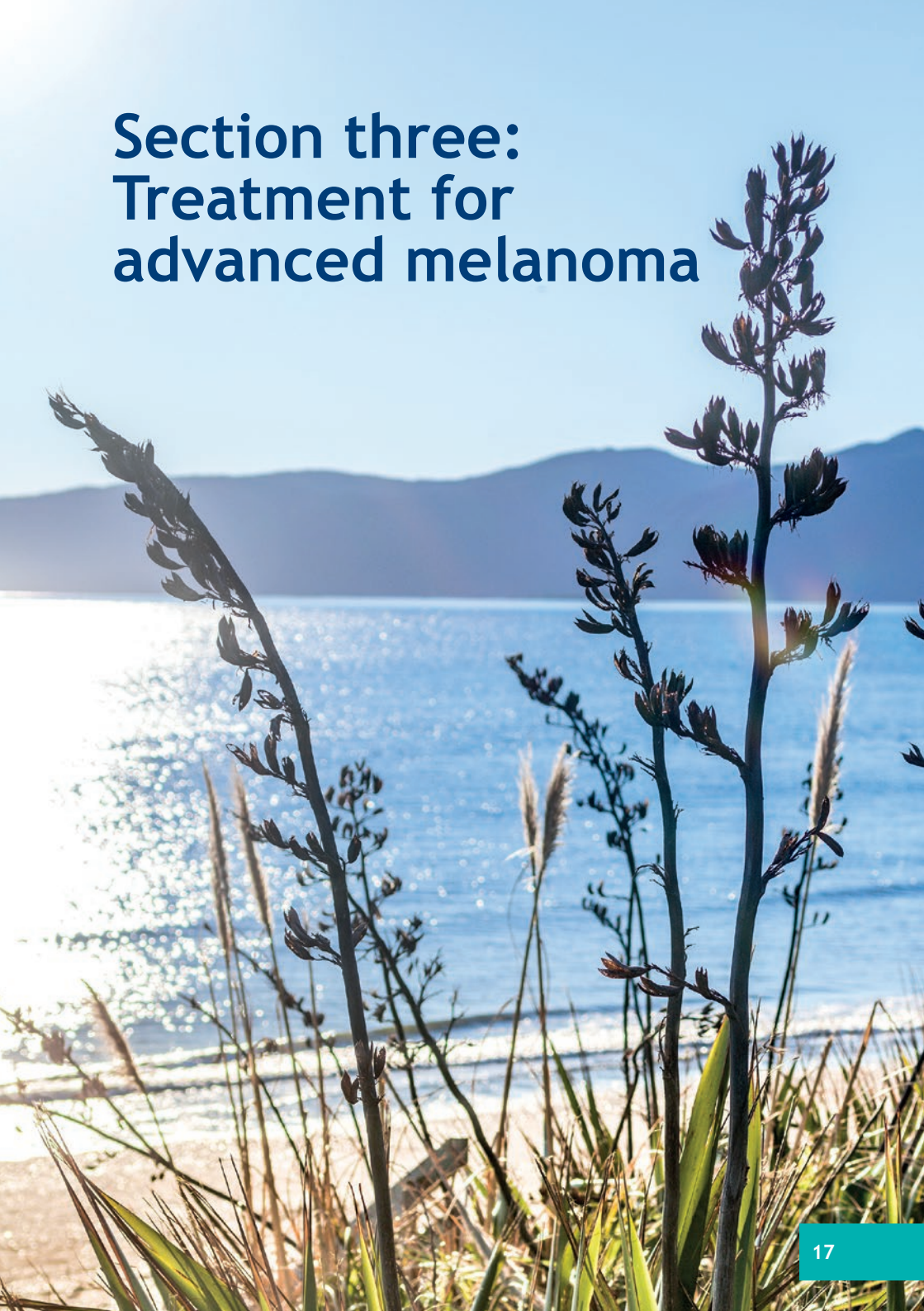
Your pathology report here:

Some questions you may want to ask your treatment team about diagnosis

You might like to find out:

- the type of melanoma you have
- the stage your melanoma is
- if your melanoma has spread
- the tests you might need
- how you can get a second opinion
- if your cancer is hereditary (passed on by your parents)
- what your prognosis is (outlook).

Section three: Treatment for advanced melanoma



Key points

- Your treatment team will advise you on the best treatment for your advanced melanoma. Treatments may include surgery, radiation treatment, targeted therapies, immunotherapy, chemotherapy and palliative care.
- Surgery can be used to assess and remove lymph nodes, help control the growth of advanced melanoma, help relieve symptoms, and treat melanoma that has spread.
- Radiation treatment uses radiation to kill melanoma cells. The radiation can be precisely targeted to melanoma sites in your body.
- A potential side effect of radiation to lymph nodes is lymphoedema.
- Targeted treatments aim to stop melanoma cells growing by targeting changes (mutations) in the genes of the cells.
- Immunotherapy boosts your body's own immune system to fight cancer.
- Funded immunotherapy and targeted treatments are only available when certain criteria are met.
- Chemotherapy uses special anti-cancer medications that destroy all cancer cells while doing the least possible damage to normal cells. The medications work by stopping cancer cells growing and reproducing.
- After treatment, it is important that you attend check-ups and protect your skin from any UV exposure from the sun. If you notice any changes in your skin or in your general health, contact your GP.

Ngā kōrero matua

- Mā tō rata koe e tohutohu mō ngā maimoatanga pai mō tō tonapuku maukaha. Ko ngā maimoatanga tērā pea ka whāia, ko te mahi hāparapara, ko te maimoatanga iraruke, ko ngā haumanu whakahāngai, ko te haumanutaunga, ko te hahau, me te atawhai taurima.
- ka āhei te whakamahi i te hāparapara ki te arotake me te tango i ngā tīpona waitinana, ki te whakahaere i te tipu o te tonapuku maukaha, ki te whakamāmā ake i ngā tohumate, me te maimoa i te tonapuku kua rauroha.
- Whakamahi ai te maimoa iraruke i te iraruke hei patu i ngā pūtau tonapuku. Ka āhei te whakahāngai tōtika i te iraruke ki ngā wāhi tonapuku i roto i tō tinana.
- Ko tētahi pānga ki te taha o te mahi iraruke kāore e kore ka puta ki ngā tīpona waitinana, ko te lymphoedema.
- Ka hāngai ngā maimoa whakahāngai ki te patu i te tipu o ngā pūtau mā te whakahāngai i ngā panonitanga (ngā iranoi) kei roto i ngā ira o ngā pūtau.
- Ka hiki te haumanutaunga i tōu ake pūnaha taunga ki te whawhai i te matepukupuku.
- Wātea anake te haumanutaunga me ngā maimoa whakahāngai inā ka āhei te whakatutuki i ētahi paearu tūturu.
- Whakamahi ai te hahau i ētahi rongoā motuhake patu matepukupuku, ka whakamate i ngā pūtau katoa me te iti noa iho o te wharanga ki ngā pūtau pai. Ka tutuki te mahi o ngā rongoā mā te whakamutu i te tipu o ngā pūtau matepukupuku, me te whakamutu i te tāruatanga o ngā pūtau matepukupuku.
- Mutu ana tō maimoatanga, he mea nui kia haere koe ki ngā hui arowhai, me te ārai i tō kiri mai i te putanga UV.

Treatment for advanced melanoma of the skin

Your treatment team will advise you on the best treatment for your advanced melanoma. Treatments may include surgery, radiation treatment, targeted therapies, immunotherapy, chemotherapy and palliative care.

Advanced melanoma means your melanoma is unlikely to be cured. However, in recent years new treatments that are more effective have been developed. These new treatments can lead to remission that may last for many months and possibly years.

Your treatment team

From the time that you are diagnosed with advanced melanoma, you may be cared for by one or more of a team of health professionals, including:

- your GP—your family/whānau doctor who will often be the first person you see
- surgeons—who remove affected tissue or lymph nodes. You may see a plastic surgeon for surgery, including skin grafting or reconstructive surgery
- **medical oncologists**—doctors who are responsible for prescribing targeted therapies, immunotherapy, chemotherapy and other aspects of cancer care
- radiation oncologists—doctors who specialise in the use of radiation treatment
- radiation therapists—people who plan and give you your radiation treatment
- a cancer nurse coordinator and/or clinical nurse specialist—a person who acts as a point of contact for you in different parts of the health service. They support and guide you and your family/whānau to keep you fully informed about your care
- outpatient nurses—nurses who work alongside doctors during their clinics.



Your treatment team may include other health care professionals such as a palliative care specialist, research nurse, social worker, psychologist, dietitian, physiotherapist, practice nurse, community health nurse, pharmacist and occupational therapist.

Talking to your treatment team

When you first learn you have cancer you may have many questions. We suggest that you think about the questions you would like to have answered and what you do not want to be told, before you visit your cancer treatment team. You may want to have a support person with you when you visit.

You can ask for a second opinion

You may want to ask another doctor about your cancer or treatment. You can ask your treatment team or GP to refer you to another cancer doctor. You are entitled to a second opinion if you want one.

How surgery is used in treatment for advanced melanoma of the skin

Surgery can be used to:

- assess and remove lymph nodes (lymph node dissection)
- help control the growth of advanced melanoma and relieve symptoms
- treat melanoma that has spread to:
 - areas of skin distant from the original melanoma
 - lymph nodes distant from the original melanoma
 - the brain
 - the liver (if the cancer has spread to a single place in the liver)
 - the lungs (if the cancer has spread to a single place in the lungs).

Plastic surgery is sometimes needed to place a skin graft over a large area where tissue has been removed.



A skin graft is being placed on the site where tissue has been removed.

Surgery to remove lymph nodes

If melanoma cells are found in your lymph nodes, your doctor may occasionally decide to remove some or all of the nodes in the affected area (lymph node dissection). This is no longer a routine procedure. This helps to prevent cancer spreading to other parts of your body. The lymph nodes are removed in hospital under a general **anaesthetic**.

For a small number of people, swelling may occur in or around an area where lymph nodes have been removed. This is called lymphoedema.

Contact your doctor if you notice swelling or have heaviness, tightness, stiffness or pain in the affected area. See page 42 for more information about lymphoedema.

How radiation treatment is used for advanced melanoma of the skin

Radiation treatment uses radiation to kill melanoma cells. The radiation can be precisely targeted to melanoma sites on your body. Treatment is carefully planned to do as little harm as possible to your normal body tissue. It may be given to shrink the tumour or to reduce the likelihood of the cancer returning to the area being treated. It can also be used to relieve symptoms such as pain or swelling. The treatment is usually given daily. The length of treatment will depend on the size and type of the cancer and your general health.



Radiation treatment staff demonstrating radiation treatment.

Side effects of radiation treatment

The side effects of radiation treatment depend on the part of your body being treated. Side effects may include tiredness and skin reddening similar to sunburn. Talk with your treatment team about any possible side effects and how to manage them. Follow the skincare advice given to you.

A potential side effect of radiation to lymph nodes is lymphoedema. See page 42 for more information about lymphoedema.

You can read more about radiation treatment in the Cancer Society booklet *Radiation/Haumanu Iraruke*.

Targeted treatments for advanced melanoma

Targeted treatments aim to stop (block or inhibit) melanoma cells growing by targeting changes (mutations) in the **genes** of a cell. These changes may be either on the surface of the cell or on the growth pathway inside the cell.

Targeted treatments work for specific gene changes, such as changes to a gene called BRAF, present in about 35 percent of all melanomas.

Changes in this gene lead to the production of a changed BRAF protein, which helps melanoma to grow. Treatments that aim to target this change and stop the melanoma cells growing and dividing are called BRAF inhibitors. Examples of BRAF inhibitor drugs are Tafenlar (Dabrafenib) and Zelboraf (Vemurafenib). The current standard of care is to combine a BRAF and MEK inhibitor, such as Vemurafenib with cobmetinib, or dabrafenib with trametinib.

Immunotherapy treatment for advanced melanoma of the skin

This is the name given to treatment that boosts the body's own **immune system** to fight cancer. Advanced melanoma can produce a substance that turns off a type of white cell (called a T-cell) so that the T-cell can no longer fight off the melanoma. The medications Keytruda (Pembrolizumab) and Opdivo (Nivolumab) are treatments that allow the T-cell to stay active (turned on) to fight melanoma cells.

“The doctors gave me six months. I’ve had Pembrolizumab and I’m going strong 18 months later. I’m feeling really good.”
Karen

Side effects of targeted treatments and immunotherapy

The side effects of targeted treatments and immunotherapy can depend on the type of treatment you are having. Talk to your doctor about the side effects that you may experience.

Targeted treatments and immunotherapy may have long-term side effects. They may affect the thyroid, causing an underactive thyroid. They can sometimes cause diabetes and lung or nerve problems. If you have specific side effects from drug treatments for melanoma you should discuss these with your oncologist, as there may be ways to manage them effectively.

The two tables below provide more in-depth information on targeted treatments and immunotherapy. Information correct at time of publishing (September 2018). Please check with your oncologist about any changes to the funded medication for your condition.

More information about targeted treatments for advanced melanoma

| Medication Pharmaceutical - (Trade name) | How the medication is given | How the medication works | Funding and availability for use in New Zealand |
|---------------------------------------------------------|--------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------|
| Dabrafenib (Tafinlar) | Tablet | Can slow or stop the growth of advanced melanoma if there are specific changes in a gene called BRAF. Can be used alone or in combination with Mekinist. | Available for use Not funded |
| Vemurafenib (Zelboraf) | Tablet | Helps to delay the growth of advanced melanoma in people who have specific changes in a gene called BRAF. | Available for use Not funded |
| Cobimetinib (Cotellic) | Tablet | Targets proteins made by a changed BRAF gene. It slows down or stops the development of your cancer. | Available for use Not funded |
| Trametinib (Mekinist) | Tablet | The MEK gene works with the BRAF gene, so drugs that block the MEK protein can also help treat melanoma that has BRAF gene changes. | Available for use Not funded |
| Imatinib (Glivec) | Tablet | Blocking receptors within a melanoma cell with a type of medication called a c-kit inhibitor, can stop melanoma cells growing and dividing. | Available for use Funded |
| Ipilimumab (Yervoy) | Tablet | Treatment for advanced melanoma with a targeted treatment called a monoclonal antibody. Helps the body's immune system to fight cancer cells. | Available for use Not funded |

More information about immunotherapies for advanced melanoma

| Medication | How the medication is given | How the medication works | Funding and availability for use in New Zealand |
|--------------------------|------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------|
| Nivolumab (Opdivo) | Given into a vein by IV infusion | Targets and blocks a protein called PD-1 on the surface of a type of immune cell called a T-cell. Blocking PD-1 triggers the body's immune system to fight cancer cells. | Available for use Funded |
| Pembrolizumab (Keytruda) | Given into a vein by IV infusion | Targets and blocks a protein called PD-1 on the surface of a type of immune cell called a T-cell. Blocking PD-1 triggers the body's immune system to fight cancer cells. | Available for use Funded |

Funded immunotherapy and targeted treatments are only available when certain criteria are met. Please discuss this with your specialist.

The availability of new therapies for advanced melanoma

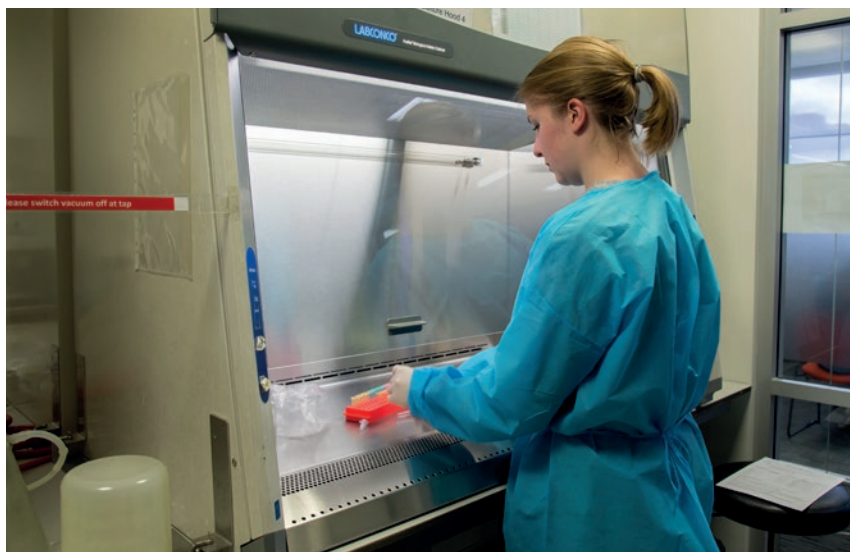
There have been many recent advances in melanoma treatment, and more are expected in the near future. Unfortunately, these treatments are expensive and PHARMAC is not able to provide funding for all the treatments that might be helpful for the management of your melanoma. You may like to ask your oncologist if there are any unfunded treatments available that may be beneficial for you. Your oncologist will be able to give you an estimate of the cost involved if you choose to fund your own treatment.

Taking part in a clinical trial

There are many new and emerging treatments for advanced melanoma. There may be clinical trials available that you could join. Sometimes these trials give you access to better medications than would be available outside a study. At other times, trials test drugs that have not been used in many people before and it may be unclear how effective the treatments are or what side effects they might have. You should discuss this with your specialist.

Clinical trials are a vital part of the search to find better treatments for cancer, to test new and modified treatments, and to see if they are better than existing treatments. In randomised clinical trials you will either receive the standard treatment currently available or the new treatment being tested.

Many people all over the world have taken part in clinical trials that have improved cancer treatments, but not all drugs tested in trials turn out to be helpful. The decision to take part in a clinical trial is yours. If you are asked to take part in a clinical trial, make sure that you fully understand the reasons for the trial and what it means for your treatment.



How chemotherapy is used for advanced melanoma

This is the treatment of cancer with anti-cancer medications. The aim is to destroy all cancer cells while doing the least possible damage to normal cells. The medications work by stopping cancer cells growing and reproducing.

Chemotherapy can be given before or after surgery and is usually given by injecting the medication into a vein (IV treatment). There are other ways of having chemotherapy, including tablets. For multiple melanoma nodules found only on an arm or a leg, chemotherapy may be given directly into the blood vessels of the limb. This is called limb infusion/perfusion and is not widely available.

Chemotherapy is occasionally used as palliative treatment for melanoma that cannot be treated by other methods.

Side effects of chemotherapy

Some medications used in chemotherapy can cause side effects. The side effects are specific to the chemotherapy medications used. They may include an increased risk of infection, feeling sick (nauseous), vomiting, feeling unwell and tired, and some thinning or loss of hair from your body and head. Generally these side effects are temporary. Talk to your treatment team about how to manage them.

If you develop a fever (a temperature of 38 degrees Celsius or over), or you feel unwell even with a normal temperature, don't wait to see what happens. Phone your cancer treatment team or hospital immediately for advice.

Ki te puta te kirikā ki a koe (he pāmahana 38 C, neke atu rānei), ki te māuiui rānei koe, ahakoa te pai o tō pāmahana, kua e whakakeke. Me wawe tonu te waea atu mō ētahi tohutohu ki tō wāhi maimoa matepukupuku, ki tō mātāi matepukupuku, ki tō tapuhi mātāi matepukupuku, ki tō hōhipera rānei.

Traditional Māori healing

Traditional healing has been an integral part of Māori culture for generations. Values, belief systems and teachings from kaumātua and tohunga have seen Māori focus on total wellbeing encompassing taha tinana, taha hinengaro, taha wairua and taha whānau (the physical domain, the domain of mind and behaviour, the spiritual domain and the family/whānau or social domain).

When some Māori are faced with tough decisions on health care or treatment, they may choose traditional healing methods. These can include rongoā Māori, romiromi or mirimiri remedies based on native plants, massage therapy and spiritual healing.

If you are thinking about using these treatments, please talk about them with your cancer treatment team. Both parties aim to provide you with the best possible care that has minimal side effects. If you have difficulty expressing your needs to your treatment providers, find someone to advocate on your behalf so that both traditional Māori healers and hospital treatment specialists are able to work together to support you on your cancer journey.

Hauora Māori

Mai rā anō te hauora Māori i noho ai hei wāhanga o te ahurea Māori. Nā ngā uaratanga, te pūnaha whakapono me ngā akoranga a ngā kaumātua me ngā tohunga i kitea ai te arotahi a te Māori ki te oranga kotahi e rarawhi ana i te taha tinana, te taha hinengaro, te taha wairua me te taha whānau.

Ka huri ētahi Māori ki ngā kaupapa hauora Māori i ētahi wā mēnā he uaua ki te whakatau ko tēhea, ko tēhea o ngā momo maimoa me whai. Tae noa rā ki te rongoā Māori, te romiromi, te mirimiri rānei, hei tauira atu. Ka hāngai katoa ki tarutaru otaota whenua me ngā rākau, te haumanu romiromi me te whakaoranga ā-wairua.

Mehemea he uaua ki te korere i o hiahia ki ngā kaiwhakarato maimoatanga, rapua tētahi tangata hei kaitaunaki mōu, kia āhei ai ngā tohunga hauora me matanga maimoa o ngā hōhipera ki te mahi ngātahi.

Pacific traditional healing

Traditional healing has long been used by Pacific people to help in recovery. It involves taking a holistic approach to treating the person, where their mental, emotional, physical and spiritual needs are looked after together, rather than as separate parts. The treatment offered to each person depends on their needs. Medicinal plants and herbs may be used during the treatment process, as well as stones and massage.

It is possible to use both Western and traditional medicine as part of your healing journey. Each has its place and benefits.

You may think that the doctor and the traditional healer do not need to know about what each other is doing. But it is important that they do in order to make sure that the medicines you are taking are working well together and they are not causing any problems. Traditional plant medicines can sometimes react with Western medications.

If you find it hard to tell your doctor or nurses about the traditional healing methods being used by your healer, it may be helpful for your doctor or nurses to talk directly to your healer or even a close family/whānau member who knows what treatments you are receiving.

Palliative care

Palliative care focuses on improving quality of life—it is not just about care at the end of life. Care can be offered in a hospital, a rest home, at home or in a **hospice**. Coordinated care is provided by specialist doctors, nurses, social workers, spiritual care workers and cultural health services. Palliative care will help:

- you to enjoy the best quality of life you can for as long as possible
- make sure that your physical, practical, emotional and spiritual needs are looked after as well as possible

- manage symptoms of your cancer
- manage side effects of treatment
- help you to feel in control of your situation
- make your time as positive as it can be for you and your family/whānau.

It is a good idea to ask for palliative care early. Dealing with concerns early rather than waiting until they become difficult to manage can help to reduce stress for both you and your family/whānau.

You may also be faced with decisions that are hard to make during your illness. The palliative care team may be able to explain things to you, and help you to find answers.

In general, palliative care services are free. There may be a charge for hire of some equipment if you are being cared for at home.

For more information on advanced cancer, you can read the Cancer Society's booklet *Advanced Cancer/Matepukupuku Maukaha* available on our website www.cancernz.org.nz.



Complementary and alternative therapies

Complementary therapies are massage, meditation, acupuncture and other relaxation methods that are used **alongside** medical treatments. They may help you to feel better and cope more easily with your cancer treatment.

“When it was painful I transported myself to the market at home with fresh fruit. I remembered songs that have no words that reminded me of home, like streams and natural sounds. I imagined myself at moments throughout my lifetime—special places on the beach, certain things we did as children. I took myself there.”
Silei

Alternative therapies include some herbal and dietary methods, which are used **instead** of medical treatment. Many are promoted as cancer cures. However, none of these methods has been proven to be effective in treating cancer.

It is important to let your treatment team know if you are taking any complementary or alternative therapies, because some treatments may be harmful if they are taken at the same time as medical treatments. For more information, see the Cancer Society’s booklet *Complementary and Alternative Medicine* on our website www.cancernz.org.nz.

How to look after yourself following treatment

Regular check-ups

Following your treatment you will need to have regular check-ups. As well as a physical examination of your skin, an important part of each



check-up will be an examination of your lymph nodes. The main locations of lymph nodes are:

- behind your knees
- in your groin
- in your armpits and around your elbow
- above your collarbone
- around your head and neck.

Lymph nodes can get enlarged if you are unwell with a cold or flu, or it may mean that cancer cells have spread to the area. It is important that any changes in your lymph nodes are checked by your GP.

Your GP should examine your entire skin surface under a good light using a dermoscope. If they do not use a dermoscope, ask them to recommend someone in their general practice who does.

When you are going to have a spot or mole checked, it is important that your skin check provider has the right skills and equipment for the job. Melanoma New Zealand has a list of accredited skin check providers around New Zealand on its website www.melanoma.org.nz/melanoma/skin-check-provider.

It is important that you be shown how to check your own skin and that you do it regularly. If you notice any changes in your skin or in your general health, contact your GP.

He mea nui kia whakaaturia koe pēhea te arowhai i tou ake kiri, he mea nui hoki me auau tonu tō arowhai. Ki te kite koe i ētahi panonitanga ki tō kiri, ki tō hauora whānui rānei, whakapā atu ki tō rata.

Protecting your skin

Exposure to UV radiation from the sun causes permanent skin damage. Levels of UV radiation in New Zealand are high. If you have melanoma it is especially important to protect your skin all year round. You can protect your skin in the following ways:



Slip on a shirt

Slip on a shirt with long sleeves. Fabrics with a tighter weave and darker colours will give you better protection from the sun.



Slip into the shade

Slip into the shade of an umbrella or a leafy tree. Plan your outdoor activities for early or later in the day when the sun's UV levels are lower.



Slop on sunscreen

Slop on plenty of broad-spectrum, water resistant sunscreen of at least SPF 30. Apply 20 minutes before going outside and reapply every two hours and especially after being in water or sweating.



Slap on a hat

Wear a hat with a wide brim or a cap with flaps. More people are sunburnt on the face and neck than any other part of the body.



Wrap on sunglasses

Choose close fitting, wrap around style sunglasses. Not all sunglasses protect against UV radiation, so always check the label for the sun protection rating.

And do not use sunbeds.

Never allow your skin to burn. Do not rely on sunscreen alone.

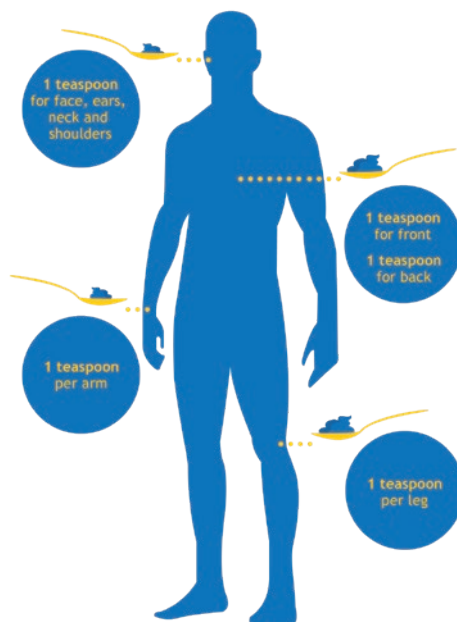
Kaua rawa e tuku tō kiri kia wera. Kaua e huri ki ngā pani ārai kiri anake.

Applying sunscreen

You need to apply your sunscreen correctly for it to be fully effective.

Apply sunscreen 20 minutes before going outside. The average-sized adult should apply at least one teaspoon to each arm, to the head including face, ears and neck), and at least a teaspoon to each leg, the front and the back of the body.

Sunscreen should be reapplied every two hours when you are outdoors and more often if you are sweating or in the water.

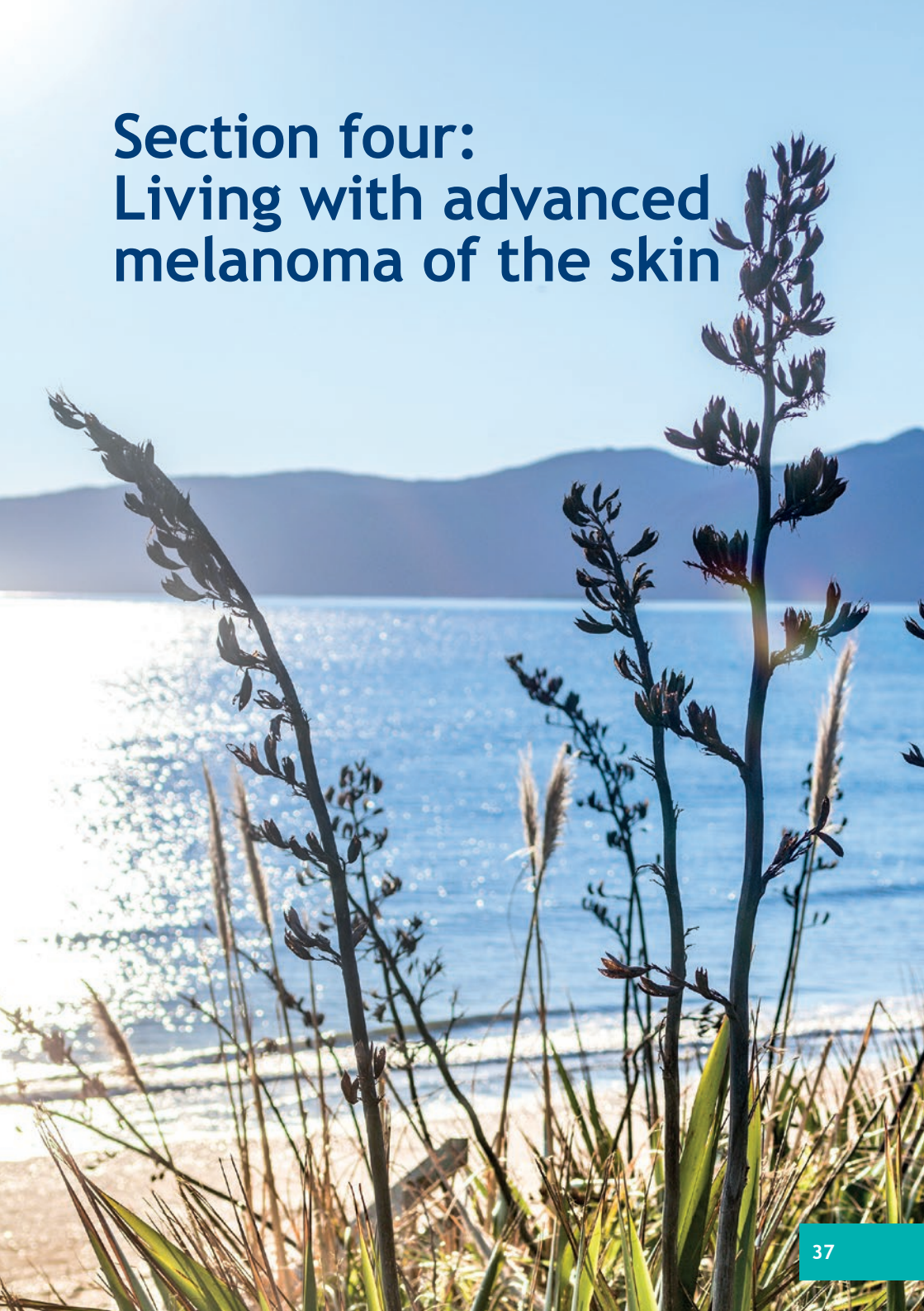


Some questions you may want to ask your treatment team after treatment

You might like to ask about:

- the treatment they would advise for your melanoma and why they think you should have that treatment
- other treatment options they would advise for you
- what they think the cost of the treatment might be
- what type of further treatment you might need and when it would begin
- if you will be cared for by a melanoma specialist
- if there are any clinical trials that you might be eligible for
- any unfunded treatments that might be helpful for you.

Section four: Living with advanced melanoma of the skin



Key points

- A diagnosis of advanced melanoma can cause physical and emotional strain. Eating well, exercising and relaxing may help to reduce stress and improve wellbeing. Addressing changes in your emotions and relationships early on is also very important.
- If you can no longer work you may have to negotiate leave, talk to your bank about a mortgage holiday, or visit Work and Income to see if you are eligible for income support.
- When you are diagnosed with advanced melanoma of the skin you may be faced with difficult decisions and emotions. This is a good time to talk to a counsellor or seek support from your local Cancer Society.
- You have access to trained interpreters and spiritual and cultural advocates should you need them.

Ngā kōrero matua

- Tērā pea ka pā te ngākau kōhuke me te taumahatanga ā-tinana i te rangona i te tohumate tonapuku maukaha. Tērā pea, mā te kai pai, te korikori tinana me te whakaparohe, e āwhina i te heke o te taumahatanga me te whakapikinga o tō toiora. He mea nui anō hoki kia whakatau moata koe i ngā rerekētanga ki ō kare ā-roto me ō hononga.
- Ki te kore koe e āhei ki te mahi, tērā pea, me whakawhiti whakaaro koe mō te whakamatuatanga ā-tau, me kōrero ki tō pēke pūtea mō tētahi hararei mōkete, me haere rānei ki te kite i Te Hiranga Tangata mō tō āheinga ki tētahi āwhina pūtea.
- Ka puta ana te tohumate ki a koe mō tō tonapuku maukaha, tērā pea ka mate koe ki te aro ki ngā whakataunga uaua, me ngā taumahatanga ā-ngākau. Koinei te wā pai ki te kōrero ki tētahi kaitohutohu, ki te rapu āwhina rānei mai i tō Kāhui Matepukupuku ā-rohe.
- E āhei ana koe ki te tono kaiwhakamāori kua raihanatia, me ngā kaitaunaki ā-wairua ā-ahurea hoki, ki te hiahia koe.



Coping with advanced melanoma symptoms and side effects

A diagnosis of advanced melanoma can cause physical and emotional strain. Eating well, exercising and relaxing may help to reduce stress and improve wellbeing. Addressing changes in your emotions and relationships early on is also very important.

For more information, read the Cancer Society's booklets *Coping with Cancer* and *Advanced Cancer / Matepukupuku Maukaha* on our website www.cancernz.org.nz.

Coping with fatigue

Fatigue is often confused with tiredness. Usually you know why you are tired and a good night's sleep solves the problem. Fatigue is overwhelming tiredness (physical and emotional) and is not relieved by rest or sleep.

Cancer-related fatigue is one of the most common side effects of cancer and its treatment. It can happen to anyone with any type of cancer and at any time, during and after treatment.

Gentle exercise can help to relieve fatigue. For more information about fatigue and suggestions on how to manage fatigue, see the Cancer Society's information sheet *Cancer-related fatigue* on our website www.cancernz.org.nz.

Changes to your eating habits

Your appetite may change when you are having treatment for advanced melanoma. Different treatments will have different effects on your eating habits. Talk to your treatment team if you are having problems with your diet. You may like to ask for a referral to a dietician if you are concerned about these changes.

For more information about diet, read our booklet *Eating Well During Cancer Treatment/Kia Pai te Kai i te Wā Maimoatanga Matepukupuku* on our website www.cancernz.org.nz.

Dealing with pain

Let your doctor or nurse know if you have any new pain or your usual pain changes in any way.

Pain is an uncomfortable and unpleasant sensation, and an emotional experience, that occurs when tissues in the body are damaged. You could experience pain for only a short period of time or you could have chronic pain that affects your quality of life. Either way it can be treated.

There is a wide variety of safe, effective options for controlling pain. If pain is not well managed, it can affect your ability to work, to enjoy normal activity and to relate to family/whānau and friends.

For more information and suggestions for managing pain, read our information sheet *Managing cancer pain* on our website www.cancernz.org.nz.



Changes in appearance after surgery

Some scars may affect your appearance, depending on their size and location. People cope with changes in appearance in different ways. Some feel self-conscious, while others are not concerned. If you are finding it difficult to adjust to any change, it is important to seek support early. Talk to your treatment team, someone close to you, or a counsellor. You can call the Cancer Information Helpline **0800 CANCER (226 237)** for information about support available in your area.

Sex and advanced melanoma

It is very difficult to predict how advanced cancer and its treatment will affect your sexual relationships. For many people there are changes that require them to adapt and develop new ways of giving and receiving sexual pleasure. Advanced cancer does not mean you will lose your sexuality. With clear communication you may still enjoy a fulfilling sexual relationship.



In many relationships one partner may be more interested in sex than the other. Advanced cancer can exaggerate this. Many people with cancer say that they feel washed out and almost completely without energy. This may be to do with the cancer itself or the treatment. In this situation you might not want to bother doing anything at all about sex. Discuss this with your partner or treatment team or, for more information, phone the Cancer Information Helpline **0800 CANCER (226 237)** and ask for the booklet *Sex and Cancer/Hokakatanga me te Matepukupuku*.

Fertility and contraception when you have advanced melanoma

You may become infertile, either temporarily or permanently, during treatment. Talk to your doctor about this before you start treatment. Despite the possibility of infertility, contraception should be used to avoid pregnancy, because there is a risk of miscarriage or birth defects for children conceived during treatment. If you are pregnant now, talk to your GP about it straight away.

Risks of developing lymphoedema after surgery and radiation treatment

Lymphoedema is a potential side effect of lymph node removal and radiation treatment to lymph nodes. The risk of developing lymphoedema after a sentinel node biopsy alone is lower than if you have a larger number of lymph nodes removed.

What is lymphoedema?

Lymphoedema is the swelling of part or parts of your body that occurs when your **lymphatic system** is not working properly. It can be caused by damage to the lymphatic system following surgery or radiation treatment, which can restrict the flow of fluid through the lymphatic system. If you develop lymphoedema, fluids collect in the tissue under your skin in your arm, leg or neck, causing it to swell. It can develop weeks, months or years after your melanoma treatment.

The lymphatic system contains many tiny channels called lymph vessels that are connected to your lymph nodes. There are lymph nodes throughout your body, including in your armpit, groin, abdomen, chest and neck. Excess fluid from your body tissue containing dead cells, cancer cells, viruses, bacteria and other waste collects in your lymph vessels and is filtered by your lymph nodes to help fight infection.

The lymphatic system

The lymphatic system is a network of small lymph nodes connected by very thin lymph vessels, which branch into every part of the body.

The lymphatic system

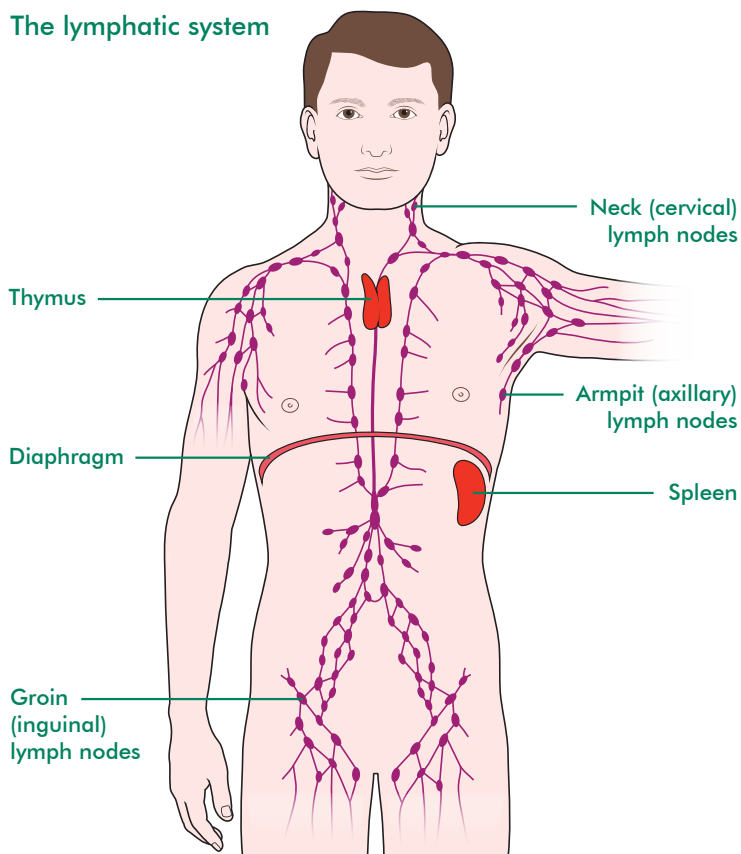


Image: Macmillan Cancer Support UK

To reduce the risk of lymphoedema, keep your skin clean and well moisturised. Avoid damage to the skin in the affected areas, especially sunburn, insect bites, blood tests and injections, and treat cuts or grazes with antiseptic.

If one of your arms is at risk of lymphoedema, avoid having your blood pressure measured on that arm. Avoid extreme temperatures and lifting heavy items. Staying active and maintaining a healthy lifestyle will reduce your risk.

Lymphoedema cannot be cured. But it can be managed with a specialised programme of exercise, massage and skin care and a properly fitted support garment or bandage. You may wish to see a lymphoedema therapist if this is available in your area.

Contact your local Cancer Society for information on lymphoedema therapists available in your area. For further information about lymphoedema, see the Cancer Society's information sheets *Understanding lymphoedema and Living with lymphoedema* on our website www.cancernz.org.nz.

Coping with feelings and relationships

Psychological, social and counselling support available to you

When you are diagnosed with advanced melanoma, you may be faced with decisions and emotions you never thought you would have to deal with. You may find it helpful to talk to a counsellor. To find support in your local area, contact your GP or your local Cancer Society, or phone the Cancer Information Helpline **0800 CANCER (226 237)**.



How families/whānau can help

As a friend or family/whānau member of someone who is diagnosed with melanoma, you are also learning to cope with your own feelings and emotions. You may want to help but not know what to do.

Here are some suggestions that may be useful.

- Learn about melanoma and its treatment. This will help you to understand what the person you are supporting is coping with.
- Be thoughtful about offering advice. Listening while they talk or just being there with them, are good ways to show you care.
- Talk about your feelings together and be honest about what worries you.
- Offer to go to appointments with them. You can be there for support, take notes or, when appropriate, take part in the discussions.
- Respect that your family/whānau member or friend may want to talk to their treatment team alone.

The Cancer Society offers a range of resources to support you. We suggest you read *'Supporting Someone with Cancer'*.

You may have changes in your employment

Whether you are able to continue working while you are having treatment for your cancer will depend on:

- the type of treatment you are having
- the stage of your cancer
- your overall health
- the type of work that you do.

Some people having treatment for their advanced melanoma are still able to go to work, while others find that they need rest or feel too unwell to continue their usual work routines. Your doctor may suggest that you consider taking some time off work during your treatment and recovery.



If you continue to work

Whether or not you tell your employer and colleagues about your cancer is up to you. If your ability to do your job is not affected, you may not want to tell your employer straightaway. Most people find that there are things that can be done to make it easier for them to continue to work. Talk with your employer about what you might need while you are having treatment.

It is useful to consider the following things if you continue to work.

- Talk to your employer about your need for time off for hospital appointments and treatment. Give them as much notice as possible and let them know when you will be able to return to work.
- Where possible, plan your treatment for later in the day or before the weekend to give you some time to recover.
- Consider the possibility of working from home on the days that you are feeling tired or fatigued.
- Having some extra help at home may mean that you have more energy for work.
- Make a list of your key duties at work so that when you are out of the office other people are able to help.

If you can no longer work

Some people choose not to work when they are diagnosed with advanced cancer or having treatment for their cancer. Even with extra time off and good planning, it is sometimes too hard to continue working. If work has been a big part of your life, it can be hard to adjust. It may be useful to talk to a friend, family/whānau member or counsellor about your feelings.

Using your work entitlements: sick leave and annual leave

When you are diagnosed with cancer you may find yourself having to negotiate sick leave, leave without pay or annual leave. These leave entitlements are outlined in your employment agreement, and minimum statutory leave requirements are contained in law (www.employment.govt.nz).

Employees get a minimum five days paid sick leave a year after the first six months of continuous employment. At any time when an employee is not entitled to sick leave, the employer can agree to the use of sick leave in advance of their entitlement, to be deducted from their next entitlement.

If you have used all your sick leave but are unable to work while you have treatment, you can request leave without pay or to use some of your annual leave.

Leave without pay is when an employer lets an employee take time off work but does not pay them for this time off. It does not stop your employment, and you can usually return to the same position, terms and conditions after taking leave without pay (unless you and your employer agree otherwise). Employees **are not entitled** to leave without pay. You can only take it if your employer agrees.

Returning to work

Deciding to return to work after you have had a period of time away can be difficult. For many people a job can start to bring back some normality, routine and financial security. It is common to feel nervous and to question whether you will be able to do your job in the same way as you did before. It is useful to discuss a plan with your manager that will help you to return to work gradually. If you can, think about what parts of your role are the most important and focus on these until you feel stronger. It is also a good idea to make sure that you have the opportunity to take regular breaks throughout the day, and that you make use of this time to have a small snack and a glass of water to help keep up your energy levels.

You might find that your co-workers respond in many ways when you go back to work. It can help to think ahead and have a plan for how you will respond to their questions so that you do not feel pressured to share information or explain things if you are not comfortable doing this.

If you have any employment difficulties, talk to Community Law or seek legal advice from someone with experience in employment law.

Financial and legal support

Financial support—benefits and entitlements

If you can no longer work because of the effects of your cancer, you may be entitled to receive income support from the Ministry of Social Development—Work and Income.

For more information, talk to a social worker or see the Cancer Society's information sheets *Benefits and entitlements* and *Benefits and entitlements: What happens when you apply for Work and Income support?*

You can get copies from our website www.cancernz.org.nz.

Talking to your bank

If you have a mortgage or other financial commitments, talk to your bank as soon as possible about how it can support you if you are unable to work for a period of time.

Personal insurance benefits

Some employment agreements offer workers the benefit of personal health insurance policies. If you have one of these and you need to leave work, talk with your human resources advisor or employer to see if this policy is still valid.

It is also a good idea to check your personal insurance policies, as you may be eligible for an early payment.

What is power of attorney?

There are two types of power of attorney.

- Ordinary Power of Attorney
- Enduring Power of Attorney (EPA)

| Ordinary Power of Attorney | Enduring Power of Attorney |
|-----------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Only valid when you have the mental capacity to manage your own affairs.</p> | <p>There are two types of EPA.</p> <ul style="list-style-type: none"> • Property • Personal care and welfare <p>They must be organised while you are able to manage your own affairs.</p> |
| <p>Attorney has power to act on specific issues only (such as managing your bank account while you are overseas).</p> | <p>Property: Authority can start immediately. You can nominate more than one EPA for property.</p> |
| <p>Can have one or more power of attorney.</p> | <p>Personal care and welfare: Authority can only start when you are no longer able to make decisions for yourself. You can only nominate one EPA for personal care and welfare.</p> |

For more information, visit these websites.

Community Law—www.communitylaw.org.nz

Citizens Advice Bureau—www.cab.org.nz/vat/gl/roi/pages/powersofattorney.aspx

How to make a will

When you are thinking about your finances and legal affairs, it can be useful to write or review your will.

A will states what happens to your belongings when you die. For those left behind, a will simplifies matters, especially if you leave assets such as property or money. A will also helps to ensure that your ‘special things’ are given to the right people after your death.

If you made a will before your cancer diagnosis, you may wish to re-view it to make sure it reflects your current wishes. If your assets are substantial, it is advised that you seek the assistance of a solicitor or trustee firm.

Do-it-yourself will kits are available, but be aware that they may not be legally binding. It is best to get legal advice on writing your will. If you live in a city, there may be a Community Law office that can help.

Advance care planning

Advance care planning is about helping you to think and talk about the end of your life, and about the treatments and care you might want.

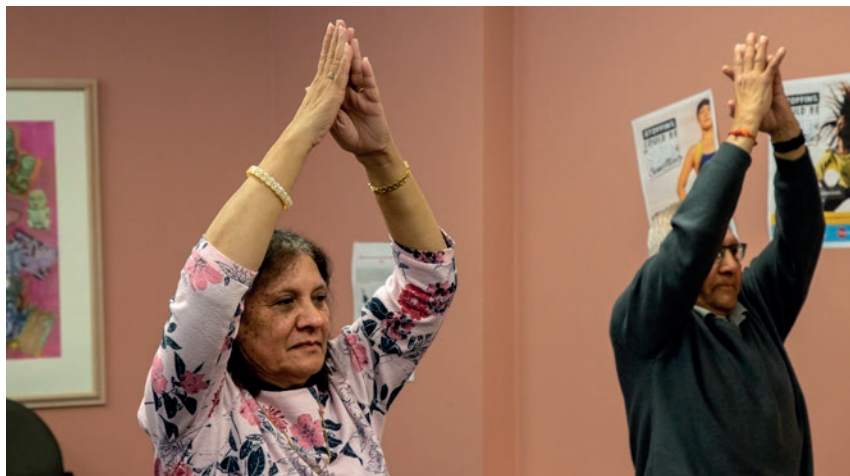
This gives you and your health care providers an opportunity to work together to ensure that your choices about treatment and care in the future are heard. An advance care plan will guide your doctors and family/whānau in making decisions if you are unable to make them yourself.

Advance care planning is voluntary—no-one can force you to do it. For more information on advance care planning, visit the Advance Care Planning website www.advancecareplanning.org.nz.

Looking after yourself when you have advanced melanoma

Advanced melanoma can cause physical and emotional strain. Eating well, exercising and relaxing may help to reduce stress and improve wellbeing.

Research indicates that regular, gentle exercise may help with fatigue and lift your mood. Talk with your doctor about what exercise is best for you.



For more information, see the Cancer Society's pamphlet *Being Active When You Have Cancer* on our website www.cancernz.org.nz.

A balanced, nutritious diet will help to keep you well and able to cope with any side effects of treatment. The Cancer Society's booklet *Eating Well during Cancer Treatment / Kia Pai te Kai te wā Maimoatanga Matepukupuku* provides useful advice about nutrition and diet during treatment. You can get a copy on the Cancer Society website www.cancernz.org.nz.

Relaxation techniques

Some people find that relaxation or meditation help them to feel better. The hospital social worker, your nurse or your local Cancer Society may know whether the hospital runs any relaxation programmes.

They may also be able to advise you on local community programmes. The Cancer Society has some relaxation resources, which are available on CD or through our website www.cancernz.org.nz.

Cultural and spiritual support

Hospitals throughout New Zealand have trained health workers available to support your spiritual, cultural and advocacy needs. They may include Māori and Pacific health workers who will work with you and your family/whānau. Hospital chaplains are available to offer support through prayer and quiet reflection.

Community health workers based at your local marae or community-based Pacific health service may be a good source of support.

Interpreting services

New Zealand's Code of Health and Disability Services Consumers' Rights states that everyone has the right to have an interpreter present during a medical consultation. If you do not speak English as your first language or you are deaf, you may find it helpful to use an interpreter when you have your hospital appointments. Speak to a member of your health care team about arranging interpreters in your local area.

Questions you may like to ask after treatment

You might like to ask:

- when you will be able to return to work
- when you will be able to drive again
- who your regular melanoma follow-up checks will be managed by
- who you should see to have a complete skin check
- how often these checks should happen
- what problems you should watch out for.

Appendix A: Suggested websites

You may be interested in looking for information about advanced melanoma on the internet. While there are very good websites, be aware that some websites may provide incorrect information.

We recommend that you begin with the Cancer Society's website (www.cancernz.org.nz) and use our links to other good cancer websites, or visit one of these websites.

- **Melanoma New Zealand (NZ)**
www.melanoma.org.nz
- **Melanoma Institute Australia**
www.melanoma.org.au
- **Macmillan Cancer Support UK**
www.macmillan.org.uk
- **Cancer Council Australia**
www.cancer.org.au
- **Health Promotion Agency**
www.hpa.org.nz
- **American Cancer Society**
www.cancer.org

The suggested websites are not maintained by the Cancer Society of New Zealand. We only suggest sites that we believe offer credible and reliable information, but we cannot guarantee that the information on such websites is correct, up-to-date or evidence-based medical information.

For more information on searching the internet, ask your local Cancer Society for a copy of the information sheet *Using the internet for cancer information and support*.

We suggest that you discuss any information you find with your medical team.

Appendix B: Understanding cancer

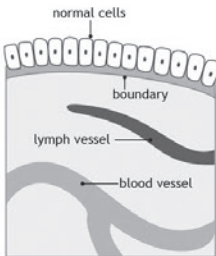
What is cancer?

Cancer is a disease of the body's cells. It starts in our genes. Our bodies are constantly making new cells to allow us to grow, replace worn-out cells and heal damaged cells after an injury.

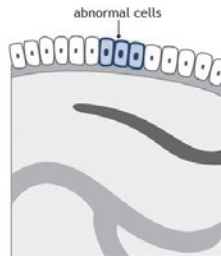
The process of making new cells is controlled by certain genes—the codes that tell our cells how to grow and behave. Cancers are caused by damage to these genes. These changes usually happen during our lifetime.

In a very small number of families, damaged genes may be passed through the generations. While these people have an increased risk of developing cancer, it does not mean they will definitely get cancer.

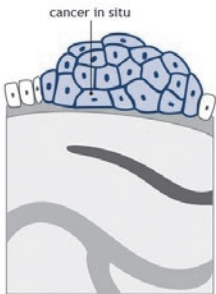
How cancer starts



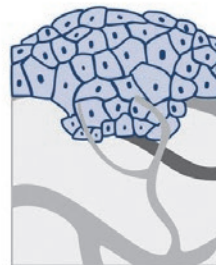
1. Normal cells



2. Abnormal cells



3. Abnormal cells multiply



4. Malignant or invasive cancer

Tumours can be benign (not cancerous) or **malignant** (cancerous). Benign tumours do not spread to other parts of the body.

How cancer spreads

A malignant tumour is made up of cancer cells. When it first develops, a malignant tumour is usually confined to its original site. This is known as the primary site. Some tumours can become quite large within their organs of origin. With growth, the tumour may spread beyond the original organ boundaries and into surrounding tissues. This is called locally advanced cancer.

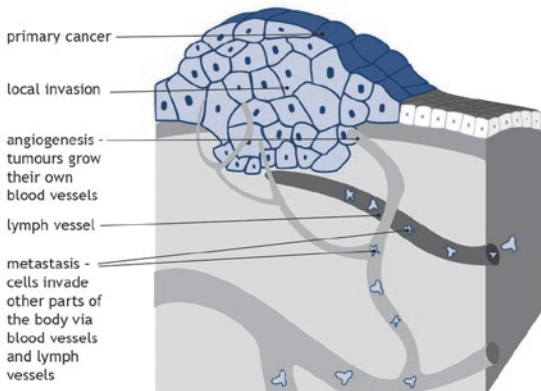
Sometimes cells move away from the original (primary) cancer through the bloodstream or lymphatic systems and start to grow in other body organs. When these cells reach a new site they may form another lump or mass. This is called a *secondary cancer* or *metastasis*. For example, if melanoma spreads to the liver, it is called a liver secondary (or metastasis).

If the only place of spread is to nearby lymph nodes, this is called regional nodal spread. Your doctor will still refer to it as melanoma even though it has spread to another part of your body.

Treatment for cancer includes surgery, radiation treatment and chemotherapy (drug treatment). Immunotherapy and **targeted treatments**, which are now used to treat some cancers, will become more important in the future.

These modes of cancer treatment can be used individually or in combination.

How cancer spreads



Appendix C: Understanding the skin

Understanding the skin

To understand melanoma of the skin it helps to understand how the skin is made up. The skin has two main layers: the **epidermis** and the **dermis**.

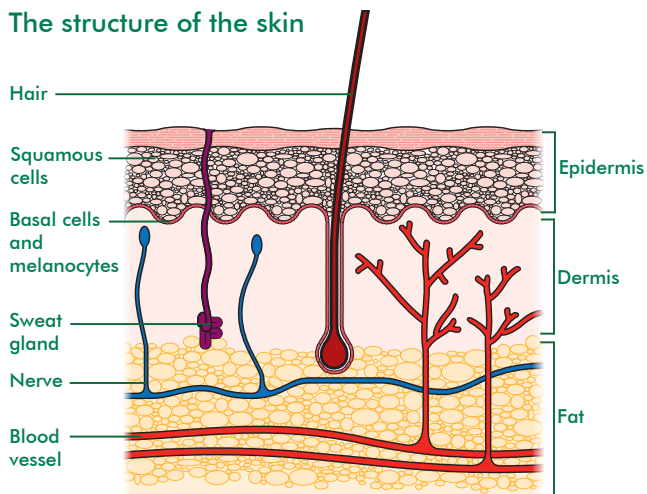


Image: Macmillan Cancer Support UK

The epidermis layer of the skin

The top layer of skin is called the epidermis. This layer contains basal cells, squamous cells and melanocytes. Basal and squamous cells are also called keratinocytes because they produce keratin, the main component of skin, hair and nails. Melanocytes are cells that produce melanin, the pigment that gives skin its colour.

The dermis layer of the skin

The layer underneath the epidermis is called the **dermis**. The dermis is made up of fibres (collagen and elastin). The dermis contains the roots of hairs, glands that make sweat and oil, blood vessels, **lymph vessels** and nerves.

Appendix D: Understanding melanoma

Who gets melanoma?

Melanoma is most common in people with fair skin. People from ethnic groups with naturally darker skin, for example Māori, Pacific and Asian people, have more protection from UV rays. However, Māori, Pacific and Asian people can still get melanoma.

According to the *World Cancer Report of 2014*, twice as many people in Australia and New Zealand are diagnosed with melanoma than in any other country in the world.

Melanoma is diagnosed most often in older people but sometimes occurs in younger adults, and occasionally in teenagers. It is very uncommon in children.

Risk factors for melanoma

Risk factors:

- fair skin and red or fair hair
- one or more severe sunburns - especially in childhood and adolescence
- use of sunbeds.

High-risk factors:

- previous skin cancers, including melanoma
- a family/whānau history of melanoma—in your immediate family
- large, irregular shaped and unevenly coloured moles (called atypical or dysplastic naevi)
- lots of moles.



Causes of melanoma

Too much sun, especially sunburn, can cause melanoma. Each time your skin is exposed to UV radiation from the sun or other sources such as sunbeds, damage can occur in your skin cells. The more exposure, the more damage.

The most important years for sun protection are during childhood and early adulthood. Exposure to UV radiation during these years greatly increases the chance of getting melanoma later in life.

For more information about being sun smart go to www.sunsmart.org.nz.

Notes

You may wish to use this space to write down any questions for or advice given by your doctors, nurses or health providers at your next appointment.

Glossary

(what does that word mean?)

Most of the words listed here are used in this booklet; others are words you are likely to hear used by doctors and other health professionals who will be working with you.

advanced cancer—cancer that is unlikely to be curable. May also be called secondary or metastatic cancer.

anaesthetic—a medication given to stop a person feeling pain. A local anaesthetic numbs part of the body; a general anaesthetic causes temporary loss of consciousness.

analgesic—a medication that relieves pain.

benign—not cancerous. Benign cells are not able to spread elsewhere in the body.

biopsy—the removal of cells or tissue from the body, so that they can then be examined under a microscope.

cells—the basic ‘building blocks’ of the body. They are able to reproduce themselves unless they are abnormal or damaged.

chemotherapy—treatment of cancer with medications that destroy cancer cells or prevent or slow further growth.

CT (computerised tomography) scan—previously known as a CAT scan. A series of X-rays taken from different angles that provide more detailed information than a normal X-ray.

dermatoscope/dermoscope—a handheld magnifying device used to examine freckles and moles.

dermis—the second layer of skin, which contains the roots of hairs, glands that make sweat and oils, blood vessels, lymph vessels and nerves.

DNA (deoxyribonucleic acid)—a molecule that contains our unique genetic code.

epidermis—the top layer of skin, which contains basal cells, squamous cells and melanocytes.

fine needle aspiration—a type of biopsy where a needle is inserted into a lump to remove cells. The cells are then examined to see if they contain melanoma cells.

genes—the codes contained in the DNA in each cell that control the way the body’s cells grow and behave. Each person’s cells have a set of many thousands of genes inherited from both parents.

hospice—a place or service that provides care for people whose illnesses are no longer curable.

immune system—the body’s natural defence system.

lymph nodes—small, bean-shaped structures that are part of the lymphatic system. Lymph nodes filter lymph fluid to remove bacteria and other harmful agents such as cancer cells.

lymph vessels—a network of vessels that connect the lymph nodes and give structure to the lymphatic system.

lymphatic system—part of the immune system, which protects the body.

malignant tumour—a tumour that is cancerous and likely to spread if not treated.

melanin—the brown pigment, produced by melanocytes, that gives skin its colour.

melanocytes—cells that produce melanin.

melanoma—cancer of the melanocytes.

metastases—tumours that develop when cancer cells break away from the original (primary) tumour. Also known as ‘secondaries’.

morphine—a strong medication used to treat pain.

MRI (magnetic resonance imaging) scan—a scan that uses radio waves and magnetic fields to produce images of the inside of a body.

oncologist—a doctor who specialises in the study and treatment of cancer.

palliative care—treatment that aims to promote comfort, relieve symptoms and maximise quality of life.

pathologist—a person who works in a laboratory to diagnose disease and understand its nature and cause.

PET (positron emission tomography) scan—a technique used to build up pictures of the metabolic activity of a body and cancer. The person is injected with a glucose solution containing a very small amount of radioactive material. The scanner can ‘see’ the radioactive substance. Damaged or cancerous cells show up as areas where the radioactive material and glucose are being taken up.

PET-CT scan—a PET scan combined with a CT scan.

primary cancer—the original cancer.

prognosis—information about the likely outcome of a person’s disease.

radiation treatment—the use of radiation to kill or damage cancer cells so that they cannot multiply.

recurrent cancer—a cancer that returns sometime after treatment has ended.

secondary cancer—cancer that is unlikely to be curable. May also be called advanced or metastatic cancer.

sentinel node—the lymph node closest to the cancer.

tissue—a collection of cells of a similar type.

tumour—a new or abnormal growth of tissue on or in a body. Tumours can be benign (not cancerous) or malignant (cancerous).

ultrasound scan—a scan that uses soundwaves to create a picture of the inside of a body.

ultraviolet (UV) radiation—the part of sunlight that causes sunburn and skin damage.

Cancer Society information and support services

The Cancer Information service is a Cancer Society phone line where you can talk about your concerns and needs with specially trained health professionals. Phone the Cancer Information Helpline **0800 CANCER (226 237)**.

Your local Cancer Society offers a range of services for people with cancer and their families/whānau. These may include:

- information and support
- volunteer drivers providing transport to treatment
- accommodation while you are having treatment away from home.

The range of services offered differs in each region, so contact your local Cancer Society to find out what is available in your area. See where each service is located at the end of this booklet.

Cancer Society of New Zealand Inc.— Te Kāhui Matepukupuku o Aotearoa

National Office

PO Box 651, Wellington 6140
Telephone: 04 494 7270

Auckland Division

PO Box 1724, Shortland Street, Auckland 1140
Telephone: 09 308 0160
Covering: Northland

Waikato/Bay of Plenty Division

PO Box 134, Waikato Mail Centre, Hamilton 3240

Telephone: 07 838 2027

Covering: Tauranga, Rotorua, Taupō, Thames and Waikato

Central Districts Division

PO Box 5096, Terrace End, Palmerston North 4441

Telephone: 06 356 5355

Covering: Taranaki, Wanganui, Manawatū, Hawke's Bay and Gisborne/East Coast

Wellington Division

52-62 Riddiford Street, Newtown, Wellington 6021

Telephone: 04 389 8421

Covering: Marlborough, Nelson, Wairarapa and Wellington

Canterbury/West Coast Division

PO Box 13450, Armagh, Christchurch 8141

Telephone: 03 379 5835

Covering: South Canterbury, West Coast and Ashburton

Otago/Southland Division

PO Box 6258, Dunedin North, Dunedin 9059

Telephone: 03 477 7447

Covering: Urban and rural Otago and Southland

Cancer Information Helpline

0800 CANCER (226 237)

www.cancernz.org.nz

Te Kāhui Matepukupuku o Aotearoa publications statement

Our aim is to provide easy-to-understand and accurate information on cancer and its treatments. Our *Living with Cancer* information booklets are reviewed and updated by cancer doctors, specialist nurses and other relevant health professionals to ensure that the information is reliable, evidence based and up to date. The booklets are also reviewed by consumers to ensure they meet the needs of people with cancer and their carers.

Other titles

Booklets

Advanced Cancer/Matepukupuku Maukaha

Radiation Treatment/Haumanu Iraruke

Cancer in the Family

Chemotherapy/Hahau

Coping with Cancer

Eating Well During Cancer Treatment/Kia Pai te Kai te wā

Maimoatanga Matepukupuku

Emotions and Cancer

Getting on with Life After Treatment/Te Hoki Anō ki tō Toioranga

Whai Muri i te Maimoatanga

Living with Dry Mouth/Te Noho me te Waha Maroke

Sex and Cancer/Hokakatanga me te Matepukupuku

Supporting Someone with Cancer/Te Manaaki i Tētahi e Māuiui ana nā te Matepukupuku

Brochures

Being Active When You Have Cancer

Questions You May Wish to Ask

Acknowledgements

Abbie Cameron

Cancer Nurse Coordinator, Christchurch Hospital

Dr Christopher Jackson

Medical Director of the Cancer Society of New Zealand and medical oncologist, Southern District Health Board

Dr Jeremy Simcock

Consultant plastic surgeon and senior lecturer with the University of Otago, Christchurch

Dr Mark Foley

Consultant at the Skin Clinic, Marlborough

Trish Leathem and Helen Kinchley

Senior melanoma nurses, Middlemore Hospital

The New Zealand Association of Plastic Surgeons (NZAPS)

Julie Holt, Jenny Burge, Kate Velenski

Cancer Society supportive care staff

Hypatia Stacy-Baynes and Angie Cairncross

Communication Advisors

Photography

Cover photo was taken by Rob Suisted

The Cancer Society wishes to thank the Christchurch Hospital for the medical photographs in this booklet and the people who had their photographs taken. We also want to thank the people from Kapiti who took part in our photo shoot and reviewed this booklet. The reviewers include specialists and people who have experienced cancer and provided many valuable suggestions.



www.cancernz.org.nz

ANY CANCER, ANY QUESTION
0800 CANCER (226 237)
Cancer Information Helpline